

# The Layperson as the Primary Health Care Practitioner

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THE PATIENT'S CENTRAL ROLE in disease control and management of illness has generated a new interest—indeed a new urgency—among health workers. Talk of making patient education a reimbursable cost in hospital care and a cost-containment factor in health maintenance organizations (HMOs) has led health planners, educators, and administrators to search the literature on patient education or to visit and observe health education programs. Some persons may be dismayed by the economic motivation, hoping for a more humanitarian reason for the upsurge of interest, but the economic argument is in itself the sum of qualitative issues—social priorities, access and quality, and the general failure of medical care to improve the status of community health.

Health education as a health care benefit—before and after the fact of disease and illness—is viewed as a potential force in helping people understand risk, assess personal and social priorities, make decisions for themselves, take the initiative for maintaining their health, and use professional resources in a self-protecting and economical manner. Effective application of health education, however, requires that we in the health professions abandon some of our earlier approaches. We must understand a new set of assumptions and social values that argue for changes in health education goals, methods, and assignment of responsibility. But this understanding will not come easily, for we must first overcome ourselves as the key deterrents to change.

Several individuals and groups in the United States are currently pioneering in self-care. Their contributions will help us appreciate the problems and potentials of translating self-care concepts into action programs.

## What is Self-Care?

My working definition of self-care is: "A process whereby a layperson can function effectively on his own behalf in health promotion and prevention and in disease detection and treatment at the level of the primary health resource in the health care system." Certain implications of this definition need emphasis. Self-care is a technology available to the community at large that includes, but is not restricted to, patients or other client categories such as HMO clients. At its

broadest base, self-care encompasses a wide range of existing skills and new skill requirements of the population at risk. It should be viewed as a universal skill set, as are the skills of literacy and numeration. Moreover, self-care is concerned with building or supplementing health skills that cover the entire spectrum of behaviors from health promotion through disease treatment and illness control or restoration. Competence within each of these areas requires a variety of functions heretofore restricted to the domain of professional services.

My definition clearly implies that self-care is an integral part of the health care system. Thus, the only distinction that can be made between providers and consumers is in the remuneration factor. At least at the moment, functional distinctions are open issues. Theoretically, no current health service function of the professional can be assured as permanent in the exclusive armamentarium of any professional worker. All functions of health professionals are open to challenge and review for their potential transfer to the lay domain.

The practice of self-care, of course, is as old as man's history. Well before the advent of specialized social functions, health care, like other aspects of survival and social development, was the individual person's responsibility. And although man eventually assigned or relinquished many functions to specialized community resources—witch doctors, priests, shamans, physicians—societies continued to rely on the individual or the family for the major portion of general health care. This is certainly true today. In several British studies, summarized by Fry (1), self-care practices were found to be nearly universal among patients. Fry concluded that "without self-care any system of health care would be swamped." It would not be surprising if comparable data for the United States were to exceed those

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for the British experience in view of Britain's greater availability of professional primary care resources. Certainly the socialization process itself inculcates the central core of health values and self-care skills that, in some instances, have been codified and fed back to society as cognitive material (2).

The motivation for self-care as a natural phenomenon in the American society, while clearly variable among subcultures (3), is strong and apparent. This motivation has provided a receptive base for the distribution of a wide range of literature designed to help people enhance their self-care skills. Some titles go back to the early 1900s and carry forward to today's well-known and increasingly sophisticated publications on health subjects, including nutrition (4), self-medication (5), diagnosis and treatment (6-9), and stress management (10). The most recent publications are emphasizing how-to-do-it skills, as well as providing information on how to use available professional resources to the client's best advantage; these publications have been stimulated by the formation of Professional Services Review Organizations (PSROs), which offer a nationwide potential for the public disclosure of data on the quality of medical care. Citizens, it is argued, must not only have the right of access to such data but must also know how to ask for it and to use it effectively (11).

Self-care as a concept, therefore, must be viewed from the levels of both personal health behavior skills and social-political skills. Both levels contribute to individual and family well-being, but the social-political concept recognizes that the etiology of many health problems is in the community domain and must be solved through social action. The person educated in self-care will therefore require a set of concepts and skills—rarely possessed by our present cadre of health professionals—including epidemiologic analysis, community organization strategies, quality control (audit systems and use review), and techniques of advocacy and control of iatrogenic disease.

It is clear that the range, emphasis, and sophistication of self-care skills will vary according to specific individual abilities and needs. Later in this paper I touch upon some of the developmental problems inherent in achieving a national effort to make self-care education useful to all citizens.

### **The Social-Health Impetus**

In line with the fashion of labeling each era according to major shifts in technology or politics, I offer the "era of self-determination" or, negatively expressed, the "era of de-professionalization" to characterize the period that we entered in the mid-1960s. We did not fully appreciate the profoundness of western society's cynicism at that time, but now we are at least conscious of it. The shattered dream of an egalitarian world, the visible rape of our environment, the realization of a supranational corporate control of international rela-

tions, the disillusionment with government, and the deterioration of privacy are among the factors leading to a sense of lack of personal control over our destinies.

In America, particularly, the civil rights movement of the 1960s and the women's liberation struggle of this decade set in motion a wide-ranging challenge to incipient racism, sexism, and associated social pathologies. These challenges to the established order of things impacted most profoundly on the institutionalized bastions of these and other values and on the professional domination inherent in them (12). And medicine as a social institution has been an outstanding example of effective social control (13). Health care as an industry with little quality control, inequitable distribution of services, and with no foreseeable limits on its appetite for the consumer's dollar became a major concern of those at especially high risk for poor access, poor quality, and exorbitant costs.

The challenge to the monopoly of medical care should not be viewed as a negative reaction to physicians or their surrogates. On the contrary, people began to sense the positive benefits of multiplying their options in health care—especially the option of self-care. These benefits include several that cannot be obtained from the professional care system. One such benefit is simply the joy of independence—the feeling of self-control and self-determination. An element of this independence is the implicit capability of people to act on the basis of their own priorities—to place health decisions into the larger complex of competing needs and interests. People can feel less guilty about deviating from professional norms of "good health behavior." They can determine their own risk mix—choosing to live according to their interests and expectations rather than according to the medical-public health morality of a totally disease-free world where "keeping healthy" is life's highest goal. They can escape the rigid, patently unrealistic, and often absurd health behavior criteria of the health professions if they so choose.

Another positive benefit of self-care is its apparent contribution toward improvement of the efficiency of the overall health care system. Public displeasure with the way health care is provided by professionals and their institutions is clearly evident. Social impetus to improve the delivery system was initially focused on consumer participation and control of health care facilities, particularly hospitals and neighborhood health centers. An elaborate technology to achieve this improvement emerged with well-publicized experiences for which varying degrees of success were reported (14). Indeed, special programs were established to train consumers in the development of health services policies and operations (an example is the New England Institute for Health Leadership Development at Boston University). However, policy control primarily attacks the fiscal aspect of power; to a lesser extent, it also attacks employment. But the power resident in the possession of clinical skills remained virtually unchal-

lenged. The client-provider relationship at the heart of the health care system was, perhaps, *affectively* revised, but there is little evidence that it was *effectively* changed; for example, that it resulted in more appropriate procedures in diagnosis and treatment. In this sense, the politically astute patient without self-care skills was still unable to participate in the domain of clinical judgment. In fact, it was a mutually acceptable ethic that consumer participation did not mean "interference" with the clinician's "technical" responsibilities—a general quid pro quo in consumer-provider negotiations regarding community involvement in health care delivery.

The foregoing situation was and still is nonsense. Patients without any or with minimal self-care competencies—despite consumer control of a health care facility—continue to relate to their care providers passively and compliantly, a manner that is often detrimental to their health. Glogow (15), for example, found that patients with a compliant, nonquestioning attitude were not the ones most likely to recover quickly. Thus, the professional's concept of a "good patient" may not be so good for the patient's health.

Social impetus for self-care skills also derives from the important shift from acute infectious disease to chronic disease. The implications for self-care are obvious. Diabetes and, more recently, hypertension are two illnesses for which self-care is crucial. Yet, in the case of hypertension there is still an unmet demand by the public to lessen dependency on the medical system by use of the relatively simple device of teaching people to take their own blood pressure and regulate their medication. Other health concerns that involve self-monitoring (16) and treatment and restorative procedures that include mental as well as dental health (17,18) are coming under public scrutiny for their self-care potential. The market demand for self-care education in chronic care can be expected to accelerate as the U.S. population continues to grow older.

Certainly the economic incentive is a major factor in the rationale for increased self-care competence among patients. Victor Fuchs, the noted health economist, has plainly made the case for increased emphasis on self-care. His argument is based on the labor-intensive character of the health care industry and, as a consequence, the importance of reducing costs through more personal health skills within the lay sector. He pointed out (19):

By changing institutions and creating new programs we can make medical care more accessible and deliver it more efficiently, but the greatest potential for improving health lies in what we do and don't do for and to ourselves. The choice is ours.

It appears that continuing the policy of overwhelming investment in manipulating the professional factor in the health care equation (improving medical education, new practice designs, personnel deployment strategies, and so on) is less wise a course than allo-

ating an equitable proportion of fiscal and technical resources to lay education in self-care. We must take a new look at the lay resource as the primary health care resource. Indeed, barring unforeseen medical breakthroughs or significant changes in patterns of disease, the lay resource may be the only reasonable means of meeting increasing demands for care of chronic diseases and the daily requirements of minor illnesses. The 1975 outlay of \$119 billion for health care is a sobering statistic that compels us to consider the self-care option as a major economic as well as a health strategy.

### **Self-Care as an Organized Enterprise**

The numbers of groups with self-care interests have grown, often unaware of each other. Self-care activities are diverse in objectives, methods, and populations served. Much overlapping and reinventing of the wheel are taking place, and as yet there are few reports on effectiveness or costs. Although there have been attempts to identify some of the organized programmatic efforts—at least in terms of organizations with a self-care or mutual-aid interest (20)—current data may represent only a small fraction of the total picture. Katz (21) has presented a useful guide to theoretical analysis of the dynamics of self-help groups.

The relative obscurity of elements of the self-care enterprise and its apparent lack of cohesion as a formal social movement can certainly be expected to undergo significant change in the near future. Promotion of demonstrations in self-care, financed by foundations and Federal contracts, surely will help to clarify the scope of public interest. National organizations, such as 4-H clubs, Red Cross, hospital auxiliaries, county agricultural agents, and HMOs, are making known their potential in self-care education.

Perhaps the most publicized program in self-care is that sponsored by the Georgetown University School of Medicine (22). This "Activated Patient Program," in Reston, Va., provides adults with information and teaches basic skills in certain aspects of primary health care, primarily preventive care. The 16-week course includes topics such as medications; impact of lifestyle on health; basic physiology; child illnesses, growth, and development; first aid; and nutrition. Counterparts of the Georgetown program are the less-publicized "Self Provider Program" in Duncan, Ariz., the "Adult Preventive Care Program" of Group Health Cooperative of Puget Sound in Seattle (23), and the adult health education course in the University of Wisconsin's Department of Family Medicine and Practice. The programmatic counterpart for children is best represented by the imaginative work of Lewis at the University of California at Los Angeles (24), who encourages children to decide by themselves when they need to seek care and to participate in decisions on managing their health problems.

Except for a modest newsletter sponsored by Georgetown University (25), there is no central resource for

the dissemination of information on self-care research or program development. Work now in progress at Yale University is directed at providing various clear-house functions.

### **Barriers to Self-Care**

Where does self-care stand in the law? What kinds of constraints or protections are available in State or Federal statutes? Recent consideration of these questions (26) revealed that apparently self-care or self-help is not acknowledged in the legal literature. Present statutes cover only the practice of medicine or surgery from the standpoint of the performance of these acts for compensation, gain, or reward that is received or expected. The laws governing health practice, written by and for the health professions, simply did not anticipate the possibility of lay potential in functions historically the province of the medical profession. However, legal constraints will foreseeably emerge through precedent, and they may ultimately require judicial challenge.

More realistic than the potential development of legal barriers to self-care are the de facto prohibitions that, although they do not have the force of the law, nonetheless impact on the public's interest and willingness to engage in self-care. An example is the oft-heard caveat about the dangers of self-diagnosis, let alone self-treatment. It is tragic that some health professionals play upon the fears and ignorance about their bodies of those laypersons who are imbued with the medical mystique. These professionals believe that patients' knowledge about their health can lead to burdensome interference with professional recommendations.

If self-care education programs are to thrive, the complementary nature of self-care and professional education must be acknowledged. For the patient who is educated in self-care, the function of medical practice must allow accommodation in order to take advantage of the potential in the partnership of patient and the health professional. Both parties are part of an integrated practice module, and both must understand the dimensions and responsibilities of this model. Etwiler's proposed doctor-patient contract (27) can help to bring about this understanding.

Perhaps the most serious barrier to self-care development lies in the two-edged reality of the self-care movement's infancy. It is a lay movement, and as such it must have the right of creative experimentation and the right to make mistakes. Many of us who want the self-care movement to grow are tempted to step in with standards, guidelines, content suggestions, and techniques. Of course we must support self-care by making conceptual and technical resources available, but how and what and when are different questions. Professional dominance can be subtle and devastating—it carries with the potential of expropriation of health (28) in the very process of "caring."

To effectively contribute to self-care, health professionals must acknowledge a new set of assumptions heretofore alien to their education, experience, and sources of gratification. Chief among these is the assumption central to self-care: that people's integrity in making health decisions and their ability to perform successfully on their own behalf take precedent over any and all existing professional values of risk reduction and disease cure. This assumption means that professionals cannot impose the view of health as good and disease as bad. This view, derived from the devil theory of disease, must be set aside—as must behavior modification strategies—in favor of individual determinism. The high value placed on the compliant patient must be transferred to the active, even resistant, patient. Consequently, health professionals will have to reorient their perspectives on health, with reduced primacy, and on their roles, technical rather than quasi-theological. No one expects this to happen without a struggle—most profoundly among the professionals themselves. Intellectually, professionals can accept much that is dissonant with their beliefs. However, their performance as a resource in self-care will demand unusual forbearance until a new source of gratification is learned—the benefits of sharing responsibility with their clients.

### **Self-Care Needs and Perspectives**

It is time for health professionals to recognize self-care programs, as well as the current status of self-care, and to gain some perspective on the movement. Self-care planning programs for school children and for adults could benefit by an objective technical resource that is uninhibited by the constraints of pre-emptive professional bias. Professionals can help in building communication links among self-care programs, and they can acquaint themselves with the requirements for revising their skills and attitudes. Symposiums, such as the one sponsored by the Institute of Social Medicine in Copenhagen in 1975, can stimulate us to experiment, demonstrate, and encourage new directions in research and health education.

Professionals can analyze their current practice and ease the declassification of medical procedures for public access in self-care. They can assist in redesigning or inventing new monitoring, diagnostic, and treatment technology (especially hardware) from the standpoint of their self-care application.

School and adult groups will need the professional resource in planning and teaching, provided that the health professional can function within an educational philosophy free of manipulation and mythology. In effect, health professionals must practice education as, in Freire's terms (29), the practice of freedom. This education must be oriented toward problem posing so that it places the burden of initiative, decision, and action on the learner.

The many different questions posed about the future needs of self-care development can now only be anticipated categorically rather than specifically. One categorical question is: How can laypersons maintain self-care skills at high levels of effectiveness over long periods? Infrequent use and changes in technology could cause serious deterioration of self-care competence. Thus, there is a need to devise a system of continuing education, with the recognition that the usually available devices of professional organizations, alumni associations, or hospital affiliations are not necessarily appropriate sources of continuing education for the community at large.

Another category of potential concern is the question of how to avoid the professionalization of the lay health resource. It is not a matter of conspiracy, but rather a concomitant of society's values regarding health skills as being in short supply and thus marketable as a public resource. Self-care education programs that are based in health service facilities are at particularly high risk of professionalization in view of the needs for manpower and the instinct of educators to extend the professional health resource.

Finally, the outcomes of self-care must become an important interest of scholars and laypersons. Here, the difficulty may be in moving away from the biases of professional criteria of health. Outcomes of self-care place the usual indicators of health into a social perspective which looks at the more integrated and transcendent values of human integrity, freedom of choice and action, achievement of health status as the layperson defines it, and self-fulfillment—happiness.

## Conclusion

The rediscovery of the lay function in health and the potential for maximizing the lay resource in self-care will require more than research on the current status of this resource, more than developmental strategies and adaptation of medical care techniques, and more than studies of the impact on existing resources. It will require value reorientation of professionals and lay persons to acknowledge and honor the social benefits of self-care beyond the health benefit; a new social contract between professionals and laypersons; and also abandonment of the arbitrary and oppressive differentiation between provider and consumer.

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